AUSTRALIAN INSTITUTE OF HOSPITAL ADMINISTRATORS

SECOND COMBINED CONFERENCE OF HEALTH ADMINISTRATORS OF NEW SOUTH WALES, SYDNEY, 21 SEPTEMBER 1977

LAW REFORM AND HOSPITAL ADMINISTRATION

Hon Justice M D Kirby

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Hon. Mr. Justice M.D. Kirby *

THE LAW REFORM COMMISSION

Establishment of the Commission. The Law Reform Commission of Australia was established in 1975. Its tasks are laid down by the *Law Reform Commission Act 1973*. They include the review, modernisation and simplification of those laws of Australia which are within the power of the Commonwealth Parliament. Most private law in Australia is a matter for the States. The Commonwealth has authority to pass laws only upon that list of subject matters which was assigned to it at federation, as amended (rarely) by referendum or expanded by judicial interpretation. Most of the law that governs hospitals and hospital administrators is State law. Such law must be altered, if at all, by the State Parliament. There is a Law Reform Commission in New South Wales. It presently has a major task to review the legal profession of this State. Perhaps the medical and paramedical profession will be next on its list. Certainly, the role of the professions is coming under increasing scrutiny. This is in part at least because the differential between the education of the professional man and the education of the rest of society has significantly diminished, especially during the last 25 years.

We are in the midst of a new age of reform. This is an uncomfortable time for the law and for those who must live under it. Society's

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values are changing rapidly. Scientific developments fuel, promote and sometimes outstrip even the changes in values. There are many ways in which the reform of the law is a matter of proper concern for hospital administrators. The movement for "industrial democracy", for example, will touch the control and government of hospitals. The rights of the mentally ill, a matter of current debate, will spill over radically to alter the administration of mental hospitals. One could expand this list. The time available constrains me to limit my observations to two subjects which are before the Australian Commission and which, directly or indirectly, may be of concern to you.

Methods of the Commission. Before I deal with these subjects, however, I want to say something about the methods used by law reform commissions. They are not always understood. They are certainly somewhat different to the usual way in which laws are prepared in our society.

Inherited from the British mode, the traditional way of preparing Australian laws was to do so in the greatest secrecy. The community first seeing the law when it was tabled in Parliament, usually on the very eve of debate. This was not done with evil intent. It was a device inherent in the system of responsible government. If governments under our system can fall, overnight, by losing their majority on the floor of Parliament, it is inevitable that Members of Parliament and those who advise them will do everything possible to minimise this risk. Even today, Bills, in the course of preparation, are usually the subject of the closest security.

This method may be inappropriate where highly controversial or moral issues have to be dealt with by Parliament or where the subject matter of the proposed law is intensely technical. The advances of science are such that the law, in many areas, becomes out of date, irrelevant or positively obstructive. In these circumstances it is necessary to design new laws. It is desirable to do so with the benefit of the best possible expert advice and, in some cases at least, the input of public opinion. Not every law reform is appropriate for this procedure.

Urgent legislation and legislation relevant to the party political debate will continue to be prepared in the traditional way. Both at a Commonwealth[1] and State[2] level in Australia, governments are permitting the circulation of legislation before enactment. The establishment of inquiries and working parties secures the best opinion of interested parties and bodies. You may not get unanimity of opinion in this way. However, it is more likely to avoid foolish mistakes and impracticable suggestions, if these procedures are adopted.

The Australian Law Reform Commission has from the start sought to involve expert and community opinion at all stages of its work. In a major task to design new methods of police investigation that would utilise the advances of science and technology such as tape recorders, videotapes and so on, a large team of police and other consultants was appointed by the Attorney-General. Furthermore public sittings were held in all parts of Australia to encourage discussion on the tentative proposals of the Commission. This is the procedure we have adopted in every reference. The Commission, although it can suggest tasks suitable for its review, works upon terms of reference that are given to it by the Commonwealth Attorney-General. The Commission is stationed in Sydney and has a total establishment of 30. There are 10 Commissioners, of whom 4 only are full-time. The Commissioners come from different avenues of the legal profession : the judiciary, government service, academic life, barristers and solicitors. The part-time members come from different States. It is a truly national law commission.

However, to avoid the perils of "lawyers myopia" we have always secured the appointment of consultants who can assist us in the interdisciplinary problems thrown up by law reform. It is undoubtedly true that law reform is too serious a matter to be

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1. J.M. Fraser, Speech to the Legal Convention, 1 July 1977 (1977) 2 *Commonwealth Record*, 863

2. W.F. Crabtree, Ministerial Statement on the *Real Property (Amendment) Bill* 1976, N.S.W. *Parlt. Debates* (Leg. Assembly) 14 September 1976, pp.800, 805.

left to lawyers alone. After consultants have been appointed, they attend meetings of the Commission and sit down as equals with the Commissioners sifting the evidence, considering the research, scrutinising proposals including draft legislation and ensuring a proper understanding of the social and special implications of the Commission's legal proposals.

The Commission was asked in 1975 to report upon new ways of coping with the drinking driver problem. Under the Constitution, the Commonwealth does not have power to enact a federal law on this subject throughout the country. The Commission's specific task was therefore limited to the Australian Capital Territory. The issues we had to face were many. They included whether random tests of drinking driving should be permitted, whether blood tests only should be permitted, how the law should cope with drivers intoxicated by drugs other than alcohol, what duties should fall upon hospitals in the taking of tests and what methods of dealing with offenders should be devised better than the knee jerk reaction of imprisonment, fines and licence suspension. All of these issues were promptly reported, within a time limit fixed by the Attorney-General. This was only possible because we had the assistance of 11 consultants from various disciplines and correspondents in all parts of the world to inform us of international developments in the law governing this universal problem. We also had much assistance from the police. The consultants ranged from the Professor of Inorganic and Physical Chemistry within the University of Tasmania, the Inspector and Director of Alcoholics & Drug Dependent Persons' Services Branch in the Department of Health in Victoria, the Professor of Analytical Chemistry in the University of New South Wales, the Queensland Government Medical Officer, the Director of Community Medicine at St. Vincents Hospital in Melbourne, a senior pharmacologist in Canberra and so on.

The law proposed in this way, with some minor modifications, has now been adopted in the Australian Capital Territory. It is the most modern and, I believe, the most effective in Australia. The points I wish to make are two. In the first place, although

the Commission is a scholarly body involved in painstaking legal research, it is not an academic institution, as such. It is part of the machinery of government. The proposals it puts forward are not simply to stimulate learned debate. They are designed actually to reform the laws by which we are governed and thereby to improve the way we live together. In some cases they seek to do no more than to catch up with the advances of science or the new problems posed by social change. In other cases they seek to rectify old wrongs and make the law simpler and fairer. "Reform" does not simply mean change. It means change for the better.[3]

The second point is that the Commission, in all its tasks, seeks interdisciplinary assistance at a top level in its most intimate deliberations. Last weekend, we completed a two-day session with the leading representatives of media and other interests in Australia. They were assisting us in the design of a uniform defamation law for Australia. In our current work on insurance contracts, we have the help of experienced insurance personnel and consumer organisations. In our task on Aboriginal tribal laws we have sought out the help of anthropologists, social workers, legal aid officers and so on. In every case expert opinion is obtained and tentative proposals are tested in the forum of the Australian community.

HOSPITAL ADMINISTRATION AND PRIVACY

The Terms of Reference. Having given you the background of the Commission, its structure and methods of operation, I now want to call attention to two specific tasks which directly affect hospital administrators. Upon one of them we have yet to report. Upon the other, the report will be tabled this day by the Commonwealth Attorney-General, Senator Durack.

During the last election campaign, the Prime Minister undertook that, if returned, the government would refer to the Law Reform

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3. A. Diamond, The Work of the Law Commission (1976) 10 *Journal of Assn. of Teachers of Law* 11 cited in The Law Reform Commission (Aust) *Annual Report*, A.L.R.C.5, p.xii.

Commission an inquiry into the laws protecting privacy in Australia. The reference was duly made.[4] The Commission is well advanced in its research on the reference. One aspect of the task has been in part discharged. It relates to the publication of private facts in the media. That subject seemed appropriate to be dealt with in the context of the proposed uniform law of defamation. The balance of the reference remains. It has many problems and many facets. Some concern you.

The problems arise essentially from the absence of well developed doctrine for the legal protection of privacy in this country and the absence of clear power in the Commonwealth to deal with this. The High Court has said that however desirable it might be to have protection of privacy, enforceable by law, no such principle exists in the common law.[5] In other words, if legal protections for privacy generally were to be developed, they would have to be developed by Parliament, not the courts.

I say the Constitution provides problems because the greatest threat to privacy as we presently know it is posed by the rapid development of computing, during the past twenty years. It is a development which has already begun in hospital administration and will continue apace. It is a universal development and thoroughly national, in Australia. Unless a national or at least uniform approach can be developed to protect privacy in the computer age, the computing industry will lack clear guidance, the costs of complying with differing privacy standards will be enormous and the avoidance of high standards for privacy protection will be a simple matter, involving nothing more than the collection of intrusive information in the States having the lowest principles of protection.

It is for this reason that the Commission is approaching its terms of reference in the broadest possible way. Whilst

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4. For the terms of reference see (1976) 50 *Aust.Law Journal* 201.

5. *Victoria Park Racing & Recreation Grounds Pty. Ltd. v. Taylor* (1934-5) 52 *Cwth. Law Reports* 9.

concentrating on matters that are within Commonwealth power, we are searching for a consistent approach to privacy protection that will be of assistance throughout the country. We are doing this with a large team of consultants who range from computing experts in Australia, a Professor of Moral Philosophy, psychologists and even one of the experts on surveillance in America who was specifically involved in the Watergate case (Professor Sam Dash).

Importance of Hospital Privacy. The reference as it concerns hospitals raises a number of issues which cannot be explored today. Hospitals are, of course, not only places for treatment. They are also employers. Rules relevant for the protection of patients' privacy may not be relevant, at least to the same extent, in respect of the privacy of employees or officers of the hospital. In hospitals, environmental privacy is a vexed issue. To many people the "privacy" of a room on their own when they are ill is a vital attribute of the privacy value. Westin, in distinguishing the components of privacy, detected two elements which are important here. The one "solitude" and the other "remove"[7]. Whilst acknowledging that this is an important matter for debate, I want to concentrate on the privacy of records and information because that is where the main thrust of the Commission's inquiry to date has been. With terms of reference of such a comprehensive magnitude, it is important to get in clear focus the value which we are seeking to protect.

The relationship between a hospital and its patient is an inevitably intrusive one. Both in physical and informational terms, the patient who seeks hospital care must surrender to hospital personnel a very great deal of his privacy. He must permit the medical, and in some cases paramedical staff, virtually unlimited discretion to "delve into the details of his life and

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7. A. Westin, *Privacy and Freedom*, 1970, New York, pp.34-5.

person".[7] The recent report of the United States Privacy Protection Study Commission put it this way :

> "As a practical matter because so much information may be necessary for proper diagnosis and treatment, no area of inquiry is excluded. In addition to describing the details of his symptoms, the patient may be asked to reveal what he eats, how much he drinks or smokes, whether he uses drugs, how often he has sexual relations and with whom, whether he is depressed or anxious, where and how long he has worked and perhaps what he does for recreation. Moreover he is expected to submit to as much direct observation and recording of what is observed as his condition suggests and as the confines of the medical-care setting permits. As the Executive Director of the American Medical Record Association observed to the Commission, "a complete medical record [today] may contain more intimate details about an individual than could be found in any single document"."[8]

If privacy is a value which reserves to the individual not only physical solitude and removal,when he desires it,but also control, to some extent, of the perceptions which society has of him, the surrender of this kind of information to medical and hospital personnel is a most vital surrender of privacy. Nobody would really dispute this. Indeed, it is inherent in the needs of diagnosis, treatment, cure and administration that detailed, personal, intrusive information should be obtained. The necessity provoked by illness of oneself or of others for whom one is responsible imposes the obligation to divulge information and permit intrusions that would be unthinkable, even criminal, in

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7. United States Privacy Study Commission, Report, *Personal Privacy in an Information Society*, July 1977, p.282 (hereafter called "U.S. Report").

8. *Ibid* p.282

another recipient. But necessity is not the only reason why citizens have been willing in the past to allow this privileged invasion of privacy. Necessity has been reinforced by protections of confidentiality to be found in moral rules, professional ethics and sometimes supported by rules of law. It is useful to mention these briefly, in order to highlight the changes that are occurring which raise the question of the adequacy of privacy protection in the hospital context.

Present Protections of Confidentiality. The moral and ethical rules that have hitherto prescribed security for medical and hospital information and limited access to it are grounded in a principle that intimate information supplied under the constraints of illness imposes duties of protection on the recipient. Whether one considers the rule to be grounded in a higher moral code or simply based on utilitarian principles (that such information will not be supplied without such a guarantee) the fact remains that a feeling of responsibility here is as old as the organised treatment of disease and disability. The Hippocratic Oath merely acknowledges a principle which was already well established in the ethical rules of ancient Greece:

> *And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets.*[9]

The rule, as a moral tenet or as a principle of professional ethics, has found its way into hospital practice in this country. It is unthinkable that a person off the street could walk into a hospital and secure the itemised record of a present or past patient. The rule is supported by legal principles

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9. Cited in [1975] *Irish Med.J.* 232

governing confidentiality. Because of the high standards of British medical practice, very few cases indeed can be found in which the principle has had to be asserted and upheld in court. When it is tested, it is variously described as arising from the fiduciary relationships between the parties[10] or the contract between the parties or the special obligation not to breach a person's confidence.[11] In two States of Australia, Victoria and Tasmania, statutes have sought to enshrine a degree of protection to medical records, at least in civil proceedings. The Victorian *Evidence Act 1958*, s.28 and the Tasmanian *Evidence Act 1910*, s.98, allow limited privilege but only to doctors and only in civil proceedings.

> "28(2) *No physician or surgeon shall, without the consent of his patient divulge in any civil suit action or proceedings (unless sanity or testimentary capacity of the patient is the matter in dispute) any information which he has acquired in attending the patient and which was necessary to enable him to prescribe or act for the patient.*"

There is no such provision in New South Wales. There is controversy about its utility because of the limited circumstances in which it applies. Some judges suggest that, quite apart from statutory protections of this kind, the courts will respect those who, feeling a moral duty to patients, decline to answer questions, unless such questions are "proper and indeed necessary ... in the course of justice, to be put and answered".[12]

Confidentiality Under Attack. In the absence of any general doctrine or principles of law to protect privacy and with only puny, scattered and limited rules to support time-honoured practice, it is relevant to identify a number of pressures which have

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10. *Cf.* Lord Riddell in "The Law and Ethics of Medical Conferences" (1926-27) 21 *Transactions of the Medico-Legal Society* (G.B.) 137.

11. *Cf. Seager v. Copydex* [1967]1 *W.L.R.* 923 at p.931

12. Lord Denning M.R. in *A.G. v. Mulholland* [1963] 2 *Q.B.* 477.

lately diminished the security of medical and hospital information. The first is the growing perception of competing moral principles, not least at a time when medical care is passing from being almost exclusively a private responsibility to, substantially, a community responsibility. The development in this country and overseas of forms of national health insurance raise for consideration the rights of the insurance schemes to have information which, at the beginning of the century, would have been regarded as intimately private. For example, whether the schemes are government or privately funded, some form of auditing control may be necessary. This requires the divulging of details about the patient and his treatment. Similarly, especially in the case of contributory schemes, it may be necessary to divulge the nature of a condition in order to decide whether, under the rules, entitlement to benefit arises or does not. More relevant is the moral question of the duty to society generally. This can arise in a number of ways. In the first place it is obviously relevant to the supply of statistical and epidemiological information. Once society takes over responsibility for individual medical treatment, society secures an even more immediate interest in the reduction of disease. In the past research was concentrated upon the prevention of infectious diseases. Since the war the focus of epidemiological research has been on chronic non-infectious diseases such as emphysema and cancer. But these require intensive medical surveillance of a substantial population over a long period of time. The moral issues are not limited to resolving the competition between an individual's right to the privacy of hospital information on him and outsiders' demands for information for society's greater good. This debate extends to demands by an individual for access to his own file. In the United States, the last decade has seen radical changes in this area. Until then, and still in this country, general medical and hospital practice was to deny the patient access to his own records. During the last ten years, the United States has seen a revolution in the provision of access to information. At a governmental level, the principle is found in the legislation known as the *Freedom of Information Act*. At a personal level, it is found in a wide range of

legislation, the most famous of which is the *Privacy Act 1974*. It may seem curious to include rights of access to information in so-called privacy legislation. A moment's reflection will explain why it is thus. Nowadays, the threats to privacy arise not so much from the physical intruder (the trespasser who enters the home or the listener at the door). The threat arises from the perception of a person through the growing mass of information accumulated on him. It is the desire to control such perceptions and to make sure they are accurate which has given rise to the United States legislation. Central to that legislation is the maintenance of security of personal information kept on people, the logging of access to ensure that security and the provision, with exceptions, of access by the individual to it so that he can check its accuracy and secure its correction, if wrong or unfair.

Certain federally aided hospitals have already come under the obligations of the access provisions. Many objections were raised to them, some of cost and some of principle. However, in nine States of the United States legislation currently grants a patient a right to inspect and in some instances obtain copies of his medical record. Colorado applies its statute not only to hospital records but records held by private physicians, psychologists and psychiatrists.[13] Some States exclude psychiatric records. Some cover only hospital records. In some cases the hospital authorities determine how much of a medical record the patients may see. Certainly, the experience of federal hospitals under the current *Privacy Act* in the United States would appear to allay fears about the number of requests for patient access and the cost of administering it. At a federal level, with a total estimated patient population of 5 million, requests for records by patients from the Bureau of Medical Services has so far numbered about 3,000.[14] The

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13. U.S. Report p.295

14. *Ibid* pp.288-9.

administrator of a large federally run psychiatric hospital in Washington D.C. estimated the number of requests for patient access during the first three months after the *Privacy Act* took effect in the United States, was about 63.[15]

The Committee of Inquiry into the Protection of Privacy established in relation to Medibank reported in December 1973 and proposed certain limited rights of access and correction.[16] The Hospital and Allied Services Advisory Council's review of that report proposed that future consideration and possibly legislation should deal with "the degree to which a patient should have access to his health records".[17]

The government has announced its intention to introduce freedom of information legislation in the current sittings of the Commonwealth Parliament. Education standards have changed rapidly, even in the past decade in Australia. Access to information about oneself may be important as a means of controlling perceptions held and thereby determining the boundaries of privacy. It seems likely to me that we will see developments in this country similar to those that are occurring in the United States and, on a different level, are about to occur in Australia.

Changes in the Profession. One of the factors promoting the need for new laws is the changed organisation of the delivery of health services and the changing technology being used, particularly in hospital relevant to patients' confidentiality and privacy. Not only has the number of visits to physicians and hospitals increased radically, the amount of information now collected and recorded has likewise increased and the numbers of persons, besides the medical-care providers who create or have access to a medical record, has grown enormously.[18] Even until

15. *Loc cit.*

16. The Committee of Enquiry into the Protection of Privacy, *Second Interim Report* 1973 p.26 (Hereafter called "The Whalan Report").

17. Hospital & Allied Services Advisory Council, *Report of Computer Committee*, 1975, p.20

the last War most confidential health information was secured by a local family physician in sole practice. In these circumstances the typical medical record was nothing more than a small card with entries showing the dates of visits, medications prescribed and charges. Security, confidentiality and privacy were protected by this system. The physician was usually able to elaborate the intimate private details of the patient's medical or emotional condition from the "safe crevices of his mind".[19] The United States Commission puts the modern problems this way :

> "In contrast, a modern hospital medical record may easily run to 100 pages. The record of a family physician may still hold information on ailments and modes of treatment, but also now note the patient's personal habits, social relationships and the physician's evaluation of the patient's attitudes and preferences, often in extensive detail".

The expansion of hospital services, the growing specialisation of the profession and of hospitals, the depersonalisation of much paramedical care, costs savings and so on have all necessitated bringing into the close personal relationship of doctor and patient, a vast range of support staff who are not automatically subject to the professional and legal constraints attaching to medical practitioners, although doubtless holding themselves generally to the same code of conduct. The absence of clear legal, professional and ethical rules to govern non-medical support staff was drawn to attention by the Whalan Committee and by the Hospital and Allied Services Advisory Council report, to which I have referred. The first recommendation of the latter was :

> *The consideration needs to be given to imposing a legal obligation of confidentiality on all staff working in the hospital or similar institution who are not health professionals and are not bound by any code of ethics or employment.*[20]

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19. U.S. Report, p.277

20. U.S. Report, p.282, footnote 22.

That abuse can occur is clearly demonstrated in the recent United States report. It points out that:

> "Hospital records are routinely available to hospital employees on request. Most of these people are medical professionals who need such access in order to do their jobs, but not all of them are. Besides the physicians, psychologists, nurses, social workers, therapists and other licensed or certified medical practitioners and para-professionals, there are nearly always medical students and other people in training programmes conducted either by the medical-care institution itself or affiliated with the institution. These people, too, have access to medical records for training or job-related purposes, as do non-professional employees and voluntary workers".

Attention is drawn to one case in 1976 where a firm was established in Denver to provide a variety of investigative services by the surreptitious acquisition of medical record information from hospitals and physicians. It was then sold to investigators and lawyers for a variety of purposes. One of the sources of information was a hospital employee. A Grand Jury condemned the "laxity of hospital security measures". The question we have to ask is whether this kind of abuse could happen or has happened here in Australia. Obviously the Advisory Council was concerned that it could. It is in no way a slight to the support staff of hospitals who do a magnificent job to say that the law and professional ethics, which developed in an earlier time need reform and revision to cope with the expansion of medical and hospital services today.

But the expansion in numbers and personnel is only one aspect of the problem. Computerisation of hospital records has already begun. As hospitals and other larger medical facilities acquire and use computers for administration and other purposes, it is inevitable that they will turn to them for confidential record-keeping. A survey of 6,000 hospitals in the United States

conducted by the American Hospital Association in 1975 indicated that approximately 1,500 had in-house computers.[21] In the two years since then, the number has undoubtedly increased. The advent of mini-computers and the growing experimentation with hospital information systems will not by-pass Australia. The flow of medical-record information between hospitals and third party payers in the United States is already heavily automated. Without legal sanctions ultimately to state society's standards and to police systems and provide redress, privacy in automated records will depend upon nothing more than good manners. It is for this reason that the United States Commission has reported to the Congress that :

> "these two trends - changing conceptions of the medical record and increasing automation - are important forces behind the Commission's conviction that now is the proper time to establish privacy protection safeguards for records that will enhance the integrity and thus the efficacy of the medical-care relationship"[22]

More Legal Inroads. In addition to the challenges mentioned above, important legal inroads already exist or are being created which diminish the privacy of information in the hands of hospitals. They include cases where "consent" is secured, although it is difficult to see how knowing consent can be given unless the person consenting has knowledge of that to which he is consenting. It includes the answers to subpoenas the obligatory answer to questions asked in court, the supply of information to auditors, insurers and others, the provision of material to researchers and the growing number of statutes which oblige a public health authority to provide information

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21. U.S. Report, p.290

22. *Ibid.*

which would formerly have been thought private and confidential. The list of notifiable diseases expands.[23] The reasons for securing this information increase in our interdependent society. Again, it is useful to look at the United States report :

> "There are few statistics indicating the number of requests for medical-record information that are not directly related to the delivery of medical care, but testimony before the Commission suggests that the number is high. For example, the Director of the medical record department of a 600-bed university teaching hospital testified that he receives an estimated 2,700 requests for medical record information each month, some 34% of them from third party payers, 37% from other physicians, 8% in the form of subpoenas, and 21% from other hospitals, attorneys and miscellaneous sources. The attorney for the [Mayo Clinic] testified that the clinic receives an estimated 300,000 requests for medical record information a year, some 88% of them patient-initiated requests relating to claims for reimbursement by health insurers".[24]

The existence of interdependence in society has led to the call for breaching the wall of confidentiality in the name of a higher value even than privacy, viz. "the public interest". On this basis the law has traditionally upheld the subpoena, the obligation to answer questions, statutory duties to provide information on communicable diseases, births and deaths, gunshot cases, drugs and so on. The latest addition, in the name of a higher public interest, is the obligation to report cases

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23. Australian Bureau of Statistics, *Official Year Book of Australia*, No. 61, 1975-76, p.466.

24. U.S. Report, p.280

of suspected baby bashing. The point to be made here is that so many have become the exceptions, that the rule itself is rendered fragile. That is the conclusion of the recent American report. It is a conclusion which should concern hospital administrators anxious to uphold at least sufficient privacy as not to damage the trusting relationship vital for the proper health care of the community.

What Can Be Done? The report of the Committee of Inquiry into the Protection of Privacy proposed limits on the contents of the suggested health insurance card, minimum collection of material by Medibank, the specification of very limited detail for claims purposes, rules relating to the retention of documents and obligations to protect confidentiality. Exceptions granted on judicial warrant were provided for, access by a person to information concerning himself was posed, an independent body to review disputes about accuracy of information was suggested and a'watchdog'agency was put forward to monitor access to personal data held in the files of Medibank. These proposals are now under the specific consideration of the Law Reform Commission.

In the United States, having reviewed record-keeping in the medical care relationship, the recent Study Commission concluded that medical records now contain more information and are more available to more users than ever before. The control which medical care providers once exercised has been greatly diluted. The comparative insulation of medical and hospital records from collateral uses, normal even a decade ago, cannot, in the opinion of the Study Commission, be entirely restored. As third parties press their demands for access to this information, the concept of "consent" to its disclosure, freely given by the individual, has increasingly less meaning. The United States Commission's answer states three objectives :

(1) To minimise intrusiveness of information held
(2) To maximise fairness in such information
(3) To create a legitimate enforceable expectation of confidentiality.

The United States faces much the same constitutional arrangement as we have in Australia. This has led its Commission to recommend attaching obligation to the granting of federal funds. This is the way in which a significant programme for privacy protection has been instituted in educational establishments.[25] I do not say whether this would be politically or legally acceptable in Australia.

The thrust of the United States recommendations is to oblige medical and hospital care providers to implement certain procedures as a condition for participation in the Medicare and Medicaid programmes. It also recommends that the States should introduce legislation to secure uniform laws for privacy protection. It recommends a criminal offence be created where any individual knowingly seeks medical record information under false pretences or through deception. To secure fairness the Commission comes down heavily in favour of patient access upon the charge of a reasonable fee. Provision is made for an individual to request correction or amendment and in the event of dispute to have the matter resolved. To protect confidentiality it is proposed that a legally enforceable duty of confidentiality should be created, existing not only in the medical profession but in all those who provide medical care. The report lists a number of exceptions to the duty of confidentiality :

* Disclosure to other medical care providers
* Disclosure to protect health or safety
* Disclosure to facilitate research
* Disclosure to auditors and evaluators
* Disclosure pursuant to compulsory reporting statutes
* Disclosure to the public (birth and death) ; and
* Disclosure pursuant to compulsory process[26]

Strict limits are suggested upon authorisation to make sure that

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25. U.S. Report, Ch.10, Record Keeping in the Educational Relationship, pp.393ff. The legislation referred to is the *Family Educational Rights and Privacy Act* 1974 (20 U.S. 1232g) known popularly as The Buckley Amendments.

26. U.S. Report pp.307ff.

the authority is "informed" and not secured under duress of any kind. Provision is also made for the logging of certain access and for obligations of physical and other security.

This will strike some as a formidable list of duties and obligations. It arises out of the clear conclusion reached by the United States Commission that :

> "The medical-care relationship in America today is becoming dangerously fragile as the basis for an expectation of confidentiality with respect to records generated in that relationship is undermined more and more. A legitimate, enforceable expectation of confidentiality that will hold up under the revolutionary changes now taking place in medical care and medical record-keeping needs to be created".[27]

It will be important for the Law Reform Commission to have the informed reaction of medical and hospital authorities throughout Australia to these proposals. We do not start this exercise with a blank page. We have the benefit of the earlier Australian inquiries, of the work of the New South Wales Privacy Committee and the conclusions of the United States Commission. We will secure the assistance of consultants including those who have already been appointed to acquaint us with the special problems in the health services area. The short review that I have given today indicates, I would suggest, that there is a problem here which will not simply go away. To do nothing is to allow the gradual erosion of an important and efficacious privilege of privacy which has existed until now. The time has come for the law, stating today's standard, to face up to the issues I have outlined and to renew itself.

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27. U.S. Report, p.308

HOSPITAL ADMINISTRATION AND TRANSPLANTATION

The Problem of Consent. I said that I would illustrate the involvement of the Law Reform Commission with your profession using two examples. The second is especially timely because it concerns a report which will be tabled later today in the Federal Parliament by the Attorney-General, Senator Durack. I am not at liberty to discuss its details, until it is tabled in the Parliament by the Attorney. I can, however, touch broadly upon the issue that was before the Commission. I shall arrange for copies of the Commission's report to be available and copies of the relevant parts of it to be distributed.

Put shortly, the Commission was confronted by the inadequacies of the law to deal with the miracles of transplantation surgery that have developed especially in the last decade. It is inappropriate to try to strike the social balances that are at stake here using the unwieldy weapons of the criminal law of murder, assault occasioning actual bodily harm and so on. The advent of ventilators and other means of artificial respiration, poses for the law the sensitive question of how "death" is to be defined in the modern age. Until now, the law appears to have been content to define death in terms of the permanent cessation of blood circulation and heartbeat. Is this still appropriate at a time when blood circulation and heartbeat can be maintained by the use of ventilators, although brain function of the patient has irreversibly ceased? Is a person in this state alive or dead? If he is alive, what is the legal position of those in the hospital who terminate the life supportive machinery?[28]

We all know that transplantation operations must be performed with great speed, often requiring severe dislocation to the hospital and necessitating a fine balance between the medical team attending to the donor and the medical team in charge of the recipient. The Commission's report deals with the difficult questions surrounding the necessity of consent by the donor or his family for transplantation purposes. On the one hand, we had urged upon us the necessity to adopt French law[29]

28. The Law Reform Commission *Human Tissue Transplants* (A.L.R.C.7) pp.52ff. ("Time of Death")

29. *Ibid.* p.41.

so that the painful obligation to obtain consent could be removed, in the case of dead donors, unless it was known that in his lifetime the deceased objected to such donation. On the other hand, it was urged upon us that the very necessity to seek consent was a healthy break upon forward, premature surgery and a reminder of the integrity of the individual human body. The Commission's solution assigns an important role to the people who are gathered here today.[30]

A Plea for Help. The Commission's methodology in the Transplant Reference brings me back to the point at which I began. We operate in a new and different way in discharging our duty to review, modernise and simplify the law. We seek the assistance of those who will be affected by the law : the experts who must work its machinery and the public who are affected by its operation. In the Transplant Reference our list of consultants is an impressive one. It includes the Professor of Anatomy at the University of Melbourne, the Professor of Surgery in the University of Queensland, the Head of the Department of Neurosurgery at the Royal Hobart Hospital, the Dean of the Faculty of Medicine within Sydney University, the Staff Renal Physician at Canberra Hospital, the Director of the Renal Unit in the Queen Elizabeth Hospital in Adelaide and so on. The attempt was made to secure different medical and hospital interests, different areas of relevant expertise and different geographical origins within this country. But we did not confine the exercise to medical practitioners alone. Recognising the moral and ethical issues raised by the reference, the Head of the Department of Moral Theology in the Catholic Institute of Sydney gave us his assistance as did the Dean of the Melbourne College of Divinity and a Professor of Philosophy. It should be said that all of the consultants gave their time without fee, their only reward being the opportunity to participate with the Commissioners in the design of an informed statute dealing with this vexed, modern problem. It was often brought home to the Commissioners, as we conducted public sittings and private discussions in all parts of Australia, that the medical profession, faced by the rapid advances in technique, feel keenly the moral issues that are

30. *Ibid*, pp.65ff and Appendix III

raised. The report draws attention to important developments which are just around the corner and will require the urgent attention of the law, if it is to give society and the medical profession due guidance. One young medical student appeared before the Commission in Perth and complained that, in the face of developments of transplantation, the looming problems of genetic engineering, embryo transplants, artificial insemination, transplantation of fetal tissue and so on, the law provides little guidance, and medical training commits these issues to private conscience or a one-hour lecture in a six-year course.[31] Society puts great burdens on those who deliver health care. The advances of technique outlined in the Commission's report, make it plain that society's duty is to respond by stating its standards so that on these vital questions, there can be no room for doubt.

The Commission is in the midst of work on references which affect you all as citizens and as hospital administrators. I hope that you will consider it to be part of your function, amidst many other pressing duties, to take the opportunity that is presented to lend your expertise, views and criticisms to the Commission thereby contribute to the renovation of the legal system and the improvement of the society which it regulates.

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31. *Ibid*, p.7